



Together, Reaching for a Cure

Summer
2007

The Childhood Brain Tumor Foundation

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Neurotransmitter

Communicating our message.

Http://www.childhoodbraintumor.org

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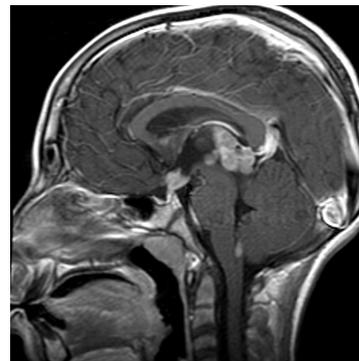
Germ Cell Tumors of the Brain

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The family of tumors known as germ cell tumors can develop anywhere in the body, most commonly in the male testicles and female ovaries, but also in other locations in the pelvis, abdomen, chest and brain. These tumors are considered to arise from nests of embryonic cells that were traveling along the primitive notochord during early fetal development down to their usual locations (ie. to the genitals), but somehow became arrested in their migration. Those tumors arising in the brain do so mainly from mid-line locations of the pineal gland (at the rear end of the third ventricle) and the suprasellar and hypothalamic region (at the front end of the third ventricle).

What causes these primitive embryonic cells to undergo transformation into cancers is not known. These tumors are found only very rarely in more than one family member, so a genetic association is not the usual reason. Of interest, however, is that these tumors are far more common in South-East Asian countries

than in North or South America or in Europe. No environmental factors have been linked to the development of these tumors, except that the drug diethylstilbestrol (DES) used several decades ago to stabilize unstable pregnancies, and known to be associated with the development of vaginal cancer in offspring of woman taking the drug during pregnancy, has also been less convincingly linked to testicular cancer in offspring. Testicular cancer (but not other forms of germ cell cancers) has been clearly associated with the failure of testicles to descend from the abdomen into the scrotal sac of young boys.



Pineal tumor with metastases to the anterior third ventricle/hypothalamus, also to the fourth ventricle.

*(Image provided by Gilbert Vézina, M.D.
Children's National Medical Center, DC)*

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Our mission is to support and fund basic science or clinical research for childhood brain tumors.

We are dedicated to heightening public awareness of this devastating disease and improving the quality of life for those that it affects by funding vital research initiatives.

Summer 2007

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- Next edition will include coverage of May Spring Biathlon and announcement of 2007 grants funded by CBTF.*

Diagnosed at Age 13, Our Son's Courageous Journey

*Written by
Jaime Banks*



In February 2005, our 13 and a 1/2 year old son Matthew, a healthy soccer player and swimmer, started complaining of a major headache that was keeping him up at night and leaving him exhausted in the morning. Within

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Germ Cell Tumors *(continued from page 1)*

The average age at which germ cell tumors of the brain present is around the onset of puberty. However, some will present in infancy and early childhood, and others present in adult life. The age at onset is important in that younger, pre-pubertal children will experience more profound damaging effects of radiation therapy - and such younger children are usually the very ones that harbor the most malignant types of CNS germ cell tumors that require more aggressive treatments in order to cure them.

The germ cell tumors of the brain represent less than 5% of childhood brain tumors, and yet are also one of the most curable of brain tumors, being exquisitely sensitive to both radiation therapy and chemotherapy. However, their very rarity, and the complex heterogeneous forms they take, has led to a poor understanding of these tumors and how best to diagnose them and treat them. Debates ensue as to when surgery should be used for these tumors, when radiation therapy should be used alone or in combination with chemotherapy (and what doses and fields of irradiation should be used), and when can milder forms of chemotherapy suffice as opposed to more intensive chemotherapies.

The Different Types (Pathology) of Germ Cell Tumors of the Brain:

One significant difficulty in understanding germ cell tumors arising in the brain is that they often contain more than one type of germ cell tumor. The most widely accepted classification of such tumors is as follows:

Pure Germinoma	65% approx. of all CNS GC Tumors
Germinoma with Mature and/or Immature Teratoma	15% approx.
Mixed Malignant Germ Cell Tumors (containing one or more of the types: Yolk sac tumor - also known as Endodermal Sinus Tumor) Choriocarcinoma Embryonal carcinoma Germinoma Mature Teratoma Immature Teratoma	20% approx.

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A Sincere Thank You

By Kal Shahateet, Luke's Dad



Kal Shahateet

I can't believe that Saturday, May 5th has come and gone. I had been training since January for the Indianapolis Mini Marathon and now, five months later and 30 pounds lighter – well, 15 pounds post-marathon, it's done. Although it was a lot of work, it was worth the effort as I've accomplished another goal in addition to raising approximately \$5,000 for the Childhood Brain Tumor Foundation.

More so than my unexpected finish time of 1:55 hours (8:52 pace), I, also, was deeply touched by the generosity of my supporters. My initial target for the CBTF was \$1,500 which a week later I raised to \$3,000 and closed out at approximately \$5,000. I've learned throughout the years that, although there are many important causes and charities in the world, anything that involves the life of a child takes precedence. People are eager to contribute their money or time – just so long as it's for a child. Children are our hope, our dream and, hopefully, our future and when something such as an illness threatens their existence we fight any way we can. It's through donations from my supporters and from others throughout the country that medical



science can continue vital research on pediatric brain tumors and other devastating diseases.

I want to whole-heartedly thank each person who donated to the CBTF in Luke's memory. It was my intention seven years ago to honor Luke's memory on the date of his seven year passing (June 2006). Seven was a milestone for me as he would have then been away from us as long as he was with us. Little did I know seven years ago that, while we may measure time via clocks and calendars, our hearts don't quite work that way. Although Luke physically isn't with us, he spiritually is. Luke and I had a long, overdue conversation last month on that 13 mile run. It was so strange, there were over 35,000 runners, but after about the 4th mile, it was only Luke and me. I could hear his voice, his encouragement and, most importantly, his laughter. Perhaps, that's why I finished the race in less than 2 hours which qualifies me for a marathon. Thank you "Habiby!!"

God bless the Childhood Brain Tumor Foundation for their mission and God bless each of you who supported me in this fundraiser.

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Diagnosed at Age 13 *(continued from page 1)*

ten days, we made three visits to our pediatrician. On the third visit, an MRI was ordered, and a tumor was seen on the scan.

That night, Matthew was admitted to Johns Hopkins Hospital. Two days later, he was diagnosed with a non-germinomatous (or mixed cell) germ (NGGCT) of the pineal region. The diagnosis was made based upon elevated AFP and bHCG levels in the blood and cerebrospinal fluid. Over the next few days, Matthew developed symptomatic hydrocephalus. He became increasingly lethargic, experienced double vision, and had difficulty keeping his eyes open. To relieve pressure in the brain, he had surgery for a third ventriculostomy, followed by placement of a VP shunt. Almost immediately thereafter, Matthew was enrolled in a Children's Oncology Group (COG) protocol that involved six alternating cycles of carboplatin/etoposide and ifosfamide/etoposide. At the end of six chemotherapy cycles, the MRI, and tumor markers in the blood and spinal fluid looked normal, and we therefore started preparing craniospinal radiation, the next step of the protocol.

Based upon earlier research, we had decided to have proton beam radiation at Mass General, convinced that this would deliver the maximum effective dose with the fewest short- and long-term side effects. We flew to Boston for pre-radiation prep, including a routing planning MRI. Back home a few days later, we got grim results. Improbably, in just one week's time, there were signs of tumor progression. Matthew was immediately placed on a salvage chemotherapy regimen to bring the tumor under control. He received two cycles of vinblastine, bleomycin and cyclophosphamide over the next two months. During this period he also had stem cells harvested, with the understanding that he would probably require a stem cell transplant down the line. After two rounds of salvage chemo, an MRI again showed disease progression. At that point, it was recommended that Matthew undergo a gross total tumor resection.

Surgery one week later at Johns Hopkins went beautifully with no complications. Matthew spoke to us as he was being wheeled out of the operating room! Three days later, he was home. Less than a week after that, we flew to Boston to begin six weeks of craniospinal proton beam radiation at Mass General. Matthew felt great through the treatments and had virtually no side effects. In between treatments, he even attended Brookline High School and took music classes. We did a lot of sightseeing and experienced the beautiful New England fall.

We came home from Boston just before Thanksgiving knowing that Matthew would require high-dose chemo with stem cell transplant. However, we hadn't bargained on what we would learn next: Routine blood work showed abnormal tumor markers in the serum with normal markers in the spinal fluid. It appeared that there was now a second tumor site in his body. Although the doctors were initially surprised, they later determined that the VP shunt, placed at diagnosis to prevent hydrocephalus, had transported tumor cells from the brain down to

the peritoneum. There were now nodules in the abdomen. At this point, we were told he needed to have not one, but two, stem cell transplants back to back.

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Matthew entered the hospital in mid-December 2005 and went through three days of high-dose chemo with carboplatin and etoposide, followed by stem cell transplant and approximately three weeks of recovery. Then he checked back into the hospital to repeat the entire process. We came home from the hospital in early March.

Since that time, Matthew has had monthly blood work, regular MRIs and spinal taps, and has remained disease-free. Having kept up with his studies through a combination of home and hospital tutoring, Matthew was finally able to return to school last fall, joining his 10th grade class.



Unfortunately, however, treatment was not without significant side effects. Two stem cell transplants with high-dose carboplatin left Matthew, a talented and aspiring musician, with progressive profound hearing loss in both ears. After months of frustration trying to get by with hearing aids, Matthew finally chose to have a cochlear implant last December. The device was turned

on one month later, and the results exceeded expectation. His hearing is back to near-normal levels and he is once again able to participate comfortably in most settings—and even enjoy music.

We are grateful to the medical teams at Johns Hopkins and Mass General who have cared for Matthew; to the doctors at Children's National Medical Center, Children's Hospital of Los Angeles and NYU Medical Center, as well as nutritionist Jeanne Wallace, who have consulted with us' to our wonderful circle of family, friends and neighbors who have supported us through this difficult time; and for the miraculous advances in scientific knowledge and medical technology that have supported Matthew's recovery.

Written by Jaime Banks, Bethesda, Maryland. Before her son's diagnosis, Jaime worked as a marketing consultant, specializing in health communications and patient education.

Germ Cell Tumors (continued from page 2)

Therefore, in over one third of cases, the patient will have tumors composed of more than one type of germ cell tumor. It is critical for treating physicians to be aware of this, because each of these components is best treated in differing ways!

Diagnosis of Germ Cell Tumors of the Brain:

Patients with **pineal region tumors** usually present with the acute effects of these tumors compressing and obstructing the nearby ventricular system, causing hydrocephalus (excess fluid in the chambers of the brain), raised pressure within the entire brain and consequently headaches and vomiting. Characteristically, certain eye changes are also noted due to downward compression of the tumor on the midbrain (Parinaud's Syndrome). A magnetic resonance imaging (MRI) scan will reveal a tumor in the pineal region – but that in itself does not confirm the diagnosis of a germ cell tumor. Other tumors can look virtually identical on MRI, such as pineoblastoma (pineal PNET), ependymoma and malignant gliomas.

Patients with **suprasellar/hypothalamic region tumors** present usually with a much longer history, sometimes over many months or even years, of vague symptoms including increased thirst and urination, increased fatigue, poor growth and declining school performance. These signs are largely due to destruction of the hormone-producing cells located in the hypothalamus and its connection down to the pituitary gland (the pituitary stalk or infundibulum). Again, an MRI scan will demonstrate a tumor in this location, but this does not confirm the diagnosis of a germ cell tumor; gliomas of the optic pathway are not infrequently confused with germ cell tumors in this location, as can other types of tumors.

One of the unique characteristics of germ cell tumors arising in the brain is their production and release of chemicals into the blood and the cerebrospinal fluid (CSF) called **tumor markers**. The presence of these tumor markers in either location can often confirm that a tumor seen in the pineal or suprasellar regions on MRI is indeed a germ cell tumor. However, nothing is ever quite that easy! There are two germ cell tumors markers in common use today, but not all germ cell tumors produce them, and some do so only in small amounts. The presence of such markers and the levels at which they are present in the blood or CSF are not absolutely diagnostic of specific germ cell tumor types. These tumor markers can thus be misleading in identifying germ cell tumors and specific germ cell tumor types, so that the results of germ cell tumor marker tests must be interpreted with caution. The germ cell tumor markers and their associated tumor types are shown below:

Alpha-fetoprotein (AFP)	Considered diagnostic of Yolk Sac Tumor (but also seen at low levels in some cases of Immature Teratoma and Embryonal carcinoma).
Human Chorionic Gonadotropin Beta (HCG-β)	Once considered diagnostic of Choriocarcinoma, but now recognized to be produced at “low” levels in pure Germinoma, as well as some cases of Immature Teratoma and Embryonal Carcinoma.

A significant problem that now exists is that some children with pure germinomas are being over-treated as more malignant tumors. This is because an HCG-β level in excess of 25mg/dl is currently, on North American and European (but not Japanese) trials, considered diagnostic of a more malignant choriocarcinoma tumor. There is no basis in fact for such an arbitrary cut off. On the contrary, it is clear that children with pure germinomas can have much higher levels of HCG-β in their blood or CSF. At Children's Hospital of Los Angeles, biopsy proven children with germinomas and with HCG-β up to almost 200mg/dl have been successfully cured with the less intensive germinoma treatments.

The Role of Surgery in the Treatment of Germ Cell Tumors of the Brain:

Unfortunately, the germ cell tumors of the brain arise in deep-seated locations that, even with modern day neurosurgical and imaging techniques, can lead to significant damage if operated upon by inexperienced hands. The rarity of these tumors means that only those neurosurgeons – and largely pediatric neurosurgeons – who work in major medical centers, have sufficient experience and expertise to tackle these tumors.

In general, **a biopsy (a small sample of tumor tissue) is essential if the MRI scan shows a tumor in the pineal or suprasellar regions, and the tumor markers in both serum and CSF are not elevated.** Patients with pineal region tumors usually present with hydrocephalus that needs to be corrected by the placement of a shunt; accordingly, many skilled neurosurgeons today will combine the placement of a third ventriculostomy (a totally internalized shunt) with a tiny biopsy of the tumor, performed through a much less invasive endoscopic procedure. However, the tumor tissue sample is often extremely small by this approach, and may not be representative of the entire tumor, thereby failing to recognize an additional component of a mixed germ cell tumor.

Attempts to remove most of the tumor by radical surgical resection have NOT been shown to improve the cure rate of patients with germ cell tumors of the brain, and are associated with higher complication rates, some of which may be very serious and irreversible. However, in the case of tumors consisting of mature or immature teratoma components, these components are not so responsive to irradiation or chemotherapy, and are indeed best eradicated by surgical resection. The best time to undertake such a surgical resection is not at initial diagnosis, but through **delayed surgical resection**, after initial chemotherapy (or in some cases initial radiation therapy) have shrunk down the other elements of the germ cell tumor, and a residual tumor mass remains indicative most likely of mature or immature teratoma.

Sometimes, the mature or immature teratoma component of the tumor is so substantial, that the tumor actually **increases** in size with initial chemotherapy. This uncommon but well recognized scenario is known as **“The Growing Teratoma Syndrome”**, and when this happens, it is critical that the treating physicians recognize it for what it is, a situation requiring prompt surgical resection. It is NOT an indication that chemotherapy has failed, and all hope for cure is lost unless immediate high dose radiation therapy or – even worse – far more intensive chemotherapy – is implemented! Resection of the teratoma should be undertaken, and then the original plan of treatment continued.

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Germ Cell Tumors (continued from page 4)

The Role of Radiation Therapy and Chemotherapy in the Treatment of Germ Cell Tumors of the Brain.

Germinomas of the brain are amongst the most radiation-curable of all tumors. The current "gold standard" is clearly radiation therapy, delivered to encompass the ventricular system of the brain (NOT the entire brain or the spinal cord, unless the patient has evidence of tumor spread to these regions) with an additional boost of irradiation to the site of the tumor. This approach will produce a cure for the tumor in over 90% of cases of germinoma of the brain. However, in pre-pubertal children, as well as children already presenting with some damage as a consequence of their tumor, even the current standard of radiation therapy treatment alone can produce some impairment of learning abilities, memory and intellectual functions. Accordingly, studies in North America, Europe and Japan in recent years have been trying to reduce the doses of radiation therapy down to a safer level, by giving the radiation therapy after a few courses of chemotherapy. Studies from New York University (Dr Jeffrey Allen) have suggested that such an approach, combining chemotherapy followed by radiation therapy *localized only to the tumor site*, will result in over a 90% cure rate in select children with localized brain germinomas. At my own institution (Children's Hospital of Los Angeles) we have used the same chemotherapy as Dr. Allen, but followed by low dose *ventricular* field irradiation and a small boost to the tumor site –with 100% survival without any relapse of the tumor. Recently, the North American Childrens Oncology Group (COG) have open a national study in which children with germinoma of the brain are randomly assigned to receive either radiation therapy alone (to the ventricular system of the brain plus a boost to the tumor site) or to receive Dr. Allen's chemotherapy followed by just local field irradiation.

Finally, the optimal treatment for those children with the more difficult **mixed malignant germ cell tumors** of the brain, continues also to be somewhat controversial. These tumors are far less sensitive to chemotherapy than germinomas, and are not cured by radiation therapy alone. The currently accepted treatment approach is to use several cycles of more intensive chemotherapy, followed by radiation therapy. Results from such an approach indicate cure rates of around 60% to 80%. The controversy surrounds how wide a field of radiation therapy needs to be applied. My own studies as well as those from European investigators, would indicate that only high dose radiation therapy *directed only to the tumor site*, need be employed (with the addition of low doses of irradiation to the ventricular system to "cover" any germinoma component). However, the current national COG trial administers full doses of irradiation to the entire brain and spine to these children – many of whom are pre-pubertal and therefore at much greater risk for long term toxicities of the radiation therapy. Even the COG Committee is now considering eliminating whole brain and spinal cord irradiation in their next Mixed Malignant Germ Cell Tumor trial, following completion of the present trial.

The Management of Children with Recurrent Germ Cell Tumors of the Brain:

Only a minority of patients with brain germinomas will develop a recurrence. This is likely to happen in patients who have received irradiation to the tumor site only (with or without chemotherapy) or, for whatever reason, have received chemotherapy only. Such patients can be virtually uniformly cured by appropriate radiation therapy. However, for those patients who have already received focal irradiation, the toxicities of the added irradiation are not minor, and must be considered carefully. For children who do develop recurrence of tumor despite prior irradiation and chemotherapy, an approach incorporating very high dose (marrow destructive) chemotherapy and blood cell rescue has been shown to be associated with 80% cure rates.

The treatment of children with recurrence of mixed malignant germ cell tumors depends upon the predominant cell type at recurrence. If germinoma, then treatment should be as indicated above for pure germinomas. If teratoma, then surgical resection will be the crucial form of treatment. If the more malignant GCT elements predominate (eg. yolk sac tumor, choriocarcinoma, embryonal carcinoma) then one has a much tougher battle ahead. The best approach employs two stages; the first, use of chemotherapy to achieve a state of minimal residual tumor; the second stage, the use of marrow ablative chemotherapy with blood cell rescue as indicated above for pure germinomas. This approach has resulted in about 50% cure rates for children with recurrent mixed malignant germ cell tumors of the brain. A critical component here is the ability to achieve a state of minimal residual tumor with further chemotherapy. It is imperative that new drugs and drug combinations be identified that will have the best chance of achieving such tumor responses. One approach that a number of institutions in North America are considering as a pilot is the combination of gemcitabine, paclitaxel and oxaliplatin – drugs that have been shown effective in recurrent germ cell tumors arising outside the brain in adults.

Conclusion:

The treatment of these rare germ cell tumors of the brain is associated with high cure rates, but their rarity and complexity demand that diagnosis and treatment be undertaken at major pediatric-oriented medical centers, or at the very least, in consultation with physicians from such centers. One must remember that one may be treating several different germ cell tumor components within the same patient's tumor, each with different biological behaviors and therefore demanding different approaches to treatment at the same time.

It is essential that an accurate diagnosis is made to ensure that a patient is neither under-treated nor over-treated. Finally, new drug programs must be developed in order to improve the cure rate for children whose germ cell tumors of the brain recur, and ultimately to employ more effective drug treatments in the initial management of such children to prevent any recurrences from the outset.

Written by Dr. Finlay, photo provided by Dr. Gilbert Vézina.

E-mail: jfinlay@chla.usc.edu

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Germ Cell Tumors (continued from page 5)

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Kellie SJ, Boyce H, Dunkel IJ, Diez B, Rosenblum M, Brualdi L and Finlay JL. Primary Chemotherapy for Intracranial Non-Germinomatous Germ Cell Tumors: Results of the Second International CNS Germ Cell Tumor Study Group Protocol. *J Clin Oncol* 22: 846-853, 2004. (On the treatment of mixed malignant germ cell tumors of the brain)

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CBTF's Stride for Life 5K/ Walk-Run and

Where: Lake Fairfax Park, Reston, VA

When: **Sunday, September 30, 2007**

5K Run/Walk starts at 9:00 a.m.

Kid's Fun Run starts at 9:15 a.m.

Same day packet pick-up and check-in: 7:30 a.m.

Day before, packet pick-up and late registration:

Saturday, September 29, 2007; 9:00 a.m. to 12:00 p.m.

Sapphire Technologies

8000 Tower Crescent Drive (Front of Bldg.)

Vienna, VA 22182

Check our Website (EVENTS) for a flyer:

www.childhoodbraintumor.org or call us at 301-515-2900

Registration available by mail and via www.Signmeup.com and

www.Active.com

Can't participate, but want to create a team to raise funds for research: <http://firstgiving.com/childhoodbraintumor> or encourage your friends to GiveOnline, see our Website's donation section.

Supreme Court rules on IDEA case

The [Washington Post](#) (5/22, A3, Barnes) reports, "The Supreme Court ruled yesterday that parents of disabled children do not have to hire lawyers to sue school districts when they attempt to ensure that their children's special needs are adequately met." After Sandee and Jeff Winkelman sued the Parma, Ohio, school district on behalf of their autistic son, Jacob, because they "could not afford an attorney to continue their dispute with the school board over its decision that Jacob's needs could be met in a public school," the U.S. Court of Appeals for the 6th Circuit "dismissed the Winkelmans' appeal on behalf of Jacob," saying they had to obtain counsel to represent their son. The Supreme Court yesterday overturned the 6th Circuit. "The court found that the federal Individuals With Disabilities Education Act (IDEA), which guarantees children a 'free appropriate public education,' gives rights to parents as well. Parents may represent themselves in federal court when disputes arise between them and a school district over what is best for the child, the court held." The case is [Winkelman v. Parma City School District](#) (pdf). The [Los Angeles Times](#) (5/22, Savage) also reports on the ruling.



Casino Night and Gala Party

A fund-raiser to benefit the
Childhood Brain Tumor Foundation

Glenview Mansion

at the

Rockville Civic Center

Saturday, November 10, 2007

7:00 p.m. – 11:00 p.m.

Evening includes casino, fabulous silent auction,
live music, buffet dinner, and open-bar.

Information to be posted on our Website:

www.childhoodbraintumor.org

If you would like to sponsor this event, please call:

301-515-2900

or E-mail: cbtf@childhoodbraintumor.org

CBTF Web Seminars

Check our Website periodically, we will be posting new Web Seminars. Contact us with topics you would find of interest regarding Web Seminars or articles:

cbtf@childhoodbraintumor.org

International Brain Tumor Alliance Walk Around the World for Brain Tumors

International Brain Tumor Awareness Week is on October 21-27. The International Brain Tumor Alliance (IBTA), established in May 2005 has created The Walk Around the World ("the Walk") event to encourage awareness worldwide. Organizations, such as, the Childhood Brain Tumor Foundation are supportive of this walk. The IBTA's goal is to have participants walk the circumference of the earth, 24,901 miles. They are asking that everyone support the brain tumor charity in their own region or the organization in which they are associated by raising funds and walking.

The CBTF's Stride for Life 5k Walk/Run and Kids Fun Run will be held on September 30, 2007. Miles ran or walked at the CBTF 5K may be counted to help achieve the goal of the International Brain Tumor Alliance's initiative, if designated so. If you are unable to participate in our 5K and would like to support our research efforts, encourage your friends to team build through a team page you develop on our Firstgiving site, <http://firstgiving.com/childhoodbraintumor>. You can also donate through CBTF's "Give Online" button, on our website donation page to help further our research efforts and other programs.

Your support for these events will help further brain tumor research and promote other important programs funded by the Childhood Brain Tumor Foundation. Each year, CBTF strives to increase funding and with your help we will achieve our goal. In our next issue we will post a webpage where participants can log the miles walked and the total funds raised or you can let us know via e-mail: cbtf@childhoodbraintumor.org.

CBTF will also announce the names of the various teams that participated in our Stride for Life and/or "the Walk" in our winter newsletter edition. So, come join us in September, lace up those sneakers and walk or run with your friends to support this wonderful initiative.

In Honor of

*Diane and Mamie Burdick
Julie Berger and Ryan Munro
Monet Castillo
Alexis Garas and Family
Samantha Janower
Shannen Jones
Terry Klein
Robert Neuhaus
Robin DeNola
Halley Meltz
Austin Mueller and Family
TJ Ragnoni*

*Roger and Bernice Packer
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Adam Schapiro
Katherine Sahateet
Kate Shipman
Gabrielle Titsworth
Brittany Truitt
Ronnie Walsworth
Bradley Warnke
Kayla Wenger
Bryan Young*

A huge thank you to our outstanding Scientific Advisors!



Brain Tumor Action Week April 26 through May 6, 2007

This year, Brain Tumor Action Week (BTAW) took place from April 26 through May 6, 2007. The North American Brain Tumor Coalition (NABTC), a network of charitable organizations, encouraged the brain tumor community to create awareness by educating the public and policymakers about three important topics, relevant to all brain tumor patients.

The issues of importance: 1.) Increase in funding for the National Institutes of Health; 2.) Protecting the research consortia that focus on brain tumor research and that play a critical role in answering critical questions and advancing new treatments; and 3.) Support for H.R 154, The Ending of the Medicare Waiting Period Act of 2007.

Patients, families and friends created awareness throughout the country using many strategies. Supporters of BTAW set up displays in malls, hospitals, or libraries for an awareness day; and wrote letters or made appointments to visit policymakers in their local offices or in Washington, D.C. to share some of the current issues relevant to the brain tumor community. Other approaches included sending letters to friends and family to encourage fundraising and support for brain tumor charities while sharing some of the issues that burden the brain tumor community.

During BTAW, activities took place in Washington, DC, such as, a Candlelight Vigil held in recognition of survivors and also patients who lost their battle to a brain tumor; and the Hidden Under their Hats display.

The Childhood Brain Tumor Foundation held its annual Spring Biathlon on May 6 to raise funds for important research and other programs supported by the CBTF. We also participated in providing informational materials for patients and staff at an Awareness Day held at Children's National Medical Center.

Remembrances

Ida Attman
 Ross Barash
 Cameo Beauchesne
 John Boyles
 Jeff Brown
 Kelley Bula
 Ria Dicker Butler
 Barbara W. Byrum
 Charles Byrum
 Catherine Cason
 Ryan Caspar
 Laira Caverly
 Joesetta Chiang
 Shirley Coleman
 Geoffrey Cornman
 Tommy Donzelli, Jr.
 Shawn Edwards
 Barbara Waxman Fiduccia
 Daniel Fiduccia
 Margo Flamini
 Doyle Garrett
 Frank Giacin
 Herman Glaser
 Colleen Martha Gormley
 Ian Hahn
 Dennis Hanlon
 William Hanlon
 Katie Harris
 Rebecca Hatef
 Salmaan Hava
 David Hayes
 Jonathan Hicks
 Erica Holm
 Tara Houston
 Russ Irvin
 Celia Janower
 Kristi Johnson
 David Keith
 Amy Kruppenbacher
 Frances Lewis
 Rebecca Lilly
 Lauren Lockard
 Kally Lyn Kusaj
 Emily Mau
 Willard Maddox
 Shamsa Mazara
 Gianna Mason
 Sgt. Milburn Matthews, Jr.
 Araminta Mustafa
 Hannah Miller
 Robert Peake
 Carson Pohlman

Tim Reynolds
 Eric Richardson
 Amy Schiller
 Emily Rocks
 Jay Rowley
 Joseph P. Sanford
 Lynda Santelli
 Simon Schoenfeld
 Luke Shahateet
 Steven Sliwerski
 Brennen Smith
 Lisa Soghomonian
 Tyler Christopher SooHoo
 Teresa Stargel
 Wesley Stefanik
 Kelly Elizabeth Sweeney
 Jaime Vanderheyden
 Matthew Wierzbicki
 Ian Hammond Williams
 David Zucker
 Mary Waugh
 Michael Wolff
 Josie Wynn

**The National Cancer Institutes
 Redesigns Clinical Trials
 Search Web site**

It is now easier to find clinical trial results by cancer type on NCI's clinical trials online portal. To see the new search features and other educational materials for patients, family members and researchers, visit:
[http://www.cancer.gov/clinical trials](http://www.cancer.gov/clinical%20trials)



Thank you for your support!

The Childhood Brain Tumor Foundation, Inc.
 Donation form or may be used to be added to our mailing list or for information requests.

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In Honor of: _____

On the occasion of: _____

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Information request: _____

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Optional Phone: _____

Please make checks payable to:
The Childhood Brain Tumor Foundation or (CBTF)
20312 Watkins Meadow Drive
Germantown, Maryland 20876
Telephone: 301.515.2900 Toll free: 877.217.4166

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Card# _____ exp. ____/____

Note: minimum charge donation is \$20

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Master Card and VISA donations for CBTF are also accepted through our secure [Give Online Button](#). American Express is only accepted via our Give Online Button on our Web site: www.childhoodbraintumor.org
Your donation is tax-deductible.

Visit us at
<http://www.childhoodbraintumor.org>

If you would like to receive our newsletter publications or other information, please notify us with your contact information. Contact us anytime.

WORKPLACE GIVING

Thank you to those who choose us as their charity!



Proud participant in the
 Combined Federal Campaign

- Combined Federal Campaign **12035** (NEW for 2007!);
- Children's Medical Charities of America (National) **12035**;
- United Way Nationwide (number will be in our next issue); and
- United Way D.C. National Capitol Area (next issue or check donor guide)

Campaign donations may be made for the United Way through the "donor option" or "donor choice." Please check with your employer in reference to United Way campaigns. We thank our donors and military for their support.

GIVE ONLINE:

Visit our Web site donation page, Give Online an easy way to donate and it is secure. Your support helps CBTF achieve success in its mission to find cures for all children with brain tumors. Childhood brain tumors are relatively rare and all of the children deserve a better quality of life and cures.

Please be sure to include your message or wishes when donating online. Through this service MasterCard and VISA donations are 100% with no fees taken by MC or VISA. Your donations are applied to the grants and programs offered by the Childhood Brain Tumor Foundation. Help us make a difference by contributing to help children with all types of brain tumors. Contact CBTF with any questions or interests: cbtf@childhoodbraintumor.org

The Childhood Brain Tumor Foundation is forever grateful to our Medical/Scientific Advisors, the Founders, volunteers, CFC and UW donors, and supporters.

Gift Matching Opportunities

Many companies offer a matching gifts program to support charitable organizations. Your human resources department can tell you if such a program exists in your organization. Generally, they have a form that would be sent to the Childhood Brain Tumor Foundation reporting a contribution, stating they will match the contribution. We return the form to the employer with the proper acknowledgment and information required.

CBTF accepts donations via **stock securities** through Bank of America Investment Services, Inc.

Contact our Broker, Steven P. Burroughs at 301-493-2893. CBTF also accepts stock securities through our GiveOnline donation button.

Vehicle Donation Program

CBTF now accepts vehicle donations. Donate online or call 866-332-1778 and designate the Childhood Brain Tumor Foundation as your charity of choice.

QUICK FACTS FOR DONATING
 You are eligible for an itemized TAX DEDUCTION. The service is totally free and includes convenient pick-up of your car, truck, or RV anywhere in the U.S.



Find out details by checking the Foundation Web site;
[Http://www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

A big thank you to those who have donated cars!!

Bequests, Planned Giving, and Trusts

Through a trust, bequest, or planned giving you can contribute to furthering the future research and programs of the
 Childhood Brain Tumor Foundation.
 By including the
 CBTF in your estate planning you can minimize your taxes.

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Contributing Editor: Colleen Snyder, Emily Durkin

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 Kal Shahateet

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 Gilbert Vézina, M.D.

Thank you to our bulk mail team for the spring issue:
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Germantown, MD 20876

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CBTF's Fall 5K

Sunday, September 30, 2007

Participating: www.childhoodbraintumor.com

(EVENTS), see page 6

Team building for support of the 5K

<http://firstgiving.com/childhoodbraintumor>

CASINO PARTY

Saturday, November 10, 2007

Summer 2007

- *Germ Cell Tumors of the Brain, Dr. Finlay; Diagnosed at Age 13, Our Son's Courageous Journey, by Jaime Banks (page 1)*
 - *A Sincere Thank You, by Kal Shahateet (page 2)*
 - *Supreme Court rules on IDEA case, upcoming events (page 6)*
 - *ITBTA, Brain Tumor Awareness, In honor of (page 7)*
 - *Remembrances, Other information (page 8, 9)*
- Next edition will include coverage of May Biathlon and announcement of 2007 grants funded by CBTF.*

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